

Assessment of Need

for children & adults with muscular dystrophy & allied neuromuscular conditions

A discussion of the main issues involved in a housing and equipment assessment

This chapter spans most of the sections in this manual and should be used in conjunction with them.

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The purpose of the assessment

The overall aim of an assessment is to:

- provide greater independence for you or your disabled child to enable you to achieve your full potential;
- help to overcome the mobility difficulties;
- identify the present and future needs to ensure that, as far as possible, the same facilities are provided as those enjoyed by non-disabled people;
- ease the role of the carer/s.

The effect of suitable housing and appropriate facilities should not be underestimated. To quote one parent from the research project *Homes unfit for children: housing disabled children and their families*:

"If you get your home right you can cope. This house is like a cocoon. It doesn't matter what is coming to us now. How can you make a tough decision in a house that's not a home? Within 24 hours of being in this house it was like WOW! She was a different child. Her confidence increased overnight. I can't describe to you the difference in Debbie".¹

Who should be involved?

There are several groups of people who need to be involved in the assessment:

- ⇒ the disabled child or adult and the family or carers;
- ⇒ the hospital, school or paediatric OT, and/or;
- ⇒ the community OT;
- ⇒ a Muscular Dystrophy Family Care Officer (FCO)/National OT Advisor;
- ⇒ a designer from the Muscular Dystrophy Adaptations & Building Design Network;
- ⇒ a grants officer.

The disabled child or adult and the family or carers

In addition to adults, it is important that any teenagers or younger children who are interested are involved in every stage and that no meetings take place without them. When contentious issues are to be discussed, it is sometimes suggested that meetings are held away from the home to exclude the family: this is a practice that should not be encouraged, unless the applicant, or the family, chooses not to be present.

The hospital, school or paediatric OT

The involvement of an OT, other than the community OT, will depend upon whether the person attends a hospital. In the case of children, staff working in a Child Development Centre, the Social Services Children's and Family Disability Team, or school may also know them. The best possible professional practice is for Health Trust/paediatric OTs and community OTs to work together; in many areas liaison is excellent. A paediatric OT is likely to have worked with the individual child and to know both the child and the parents. This, together with insight into the needs of children and knowledge of children's equipment, will result in a first-class assessment to pass on to the community OT, who arranges for this information to be included in the adaptation scheme.

The community OT

Frequently, OTs working in the community are placed in a difficult position, when they are asked to assess the needs and to worry about the budgets at the same time. However, the OT role is very clearly that of an advocate and the prime function is to assess the need. This is set out in the *Code of Ethics and Professional Conduct for OTs* which states:

“Services should be client centred and needs led”.

“When relevant and appropriate, occupational therapists should negotiate and act on behalf of the clients in relation to upholding and promoting the autonomy of the individual”.

... *“Occupational therapists have a duty to take reasonable care for clients whom they accept for treatment/intervention.*

Every client should have a clearly recorded assessment of need and objectives of treatment/intervention.

Occupational therapists should always record unmet needs.

Failure to do so would be considered professionally unacceptable”.

... *“Occupational therapists should state and substantiate their views to employers about resource and service deficiencies which may have implications for clients and carers”.*²

The community OT is, in fact, the key person in the assessment process because, although others can make recommendations, unless the community OT agrees that the need exists, the work will not be covered by a grant.

A Muscular Dystrophy Family Care Officer (FCO)/National OT Advisor

The Muscular Dystrophy Campaign employs FCOs, with either a social work or healthcare background, to work with families with muscular dystrophy or an allied neuromuscular condition. Their knowledge of the disabilities and their experience of the wide range of problems encountered is a useful resource, not only for the disabled person and the family but also for the other professionals working with them. In addition, the National OT Advisor is available to help, when necessary. Their contact details are included in the address list in Chapter 18.

OTs and other professionals working with disabled people have a very broad knowledge of disability, but cannot be expected to be experts in relation to every type of physical disability, or to know the most relevant solutions to difficulties associated with each medical condition. Competent professionals recognise this and are always keen to ask for the advice of a specialist worker who has greater experience in a particular field. Several years ago, during a housing survey among families with muscular dystrophy and allied neuromuscular conditions, many of the respondents expressed the following opinions:

"The Local Authority - even if willing - works with too wide a range of disabilities to know specialist answers".

"A specialist in muscular dystrophy knows the needs in the future, not what others appear to see when assessing".

A designer from the Muscular Dystrophy Adaptations & Building Design Network

Using an architectural designer with specialist knowledge of planning housing and facilities for people with muscular dystrophy and allied neuromuscular conditions will be invaluable; this innovative service is discussed in detail in Chapter 13.

A grants officer

Local authorities (LAs) adopt different procedures, but if grants officers are going to question the OT's assessment, it is helpful for them to attend one of the initial meetings. It is more constructive to be aware from the outset, rather than at a later date, of any item that will not be covered by the grant. In addition, if grants officers are present when Disability Needs forms are completed (see Chapter 10), they will have a greater understanding of the needs, which will be essential to help to justify the cost of these expensive schemes. Although many Social Services Departments will have a similar form, it will not highlight the details specific to neuromuscular conditions.

Starting the assessment process

The aim is to plan ahead, so that the adaptations are completed by the time that they are needed. Therefore, the timing is influenced not only by the physical disability – and in many cases by its progression – but also by the length of the adaptations process. The start of the assessment process is, therefore, influenced by the following:

- ⇒ the expected time-scale and delay;
- ⇒ the timing of adaptations for children;
- ⇒ the timing of adaptations for adults.

The expected time-scale and delay

This is considered first because it is usually a surprise to people anticipating the need for adaptations, to know how long the process takes. In most areas it would not be pessimistic to anticipate that the time from the first referral to the Social Services Department to completion of the building work is likely to be 2 years. This time-scale will be a problem to any family where there has been a delay in diagnosis or where re-housing has been delayed.

After the lengthy procedure of planning the scheme, there is frequently a delay between the submission of the paperwork for the grant (the plans, estimates for the building work and equipment, formal grant application, etc.) and grant approval. This is usually because the Grants Department is waiting for more money to become available in the next financial year and the delay cannot be prevented. This underlines the importance of starting the adaptation process in good time before the improved facilities are needed.

The timing of adaptations for children

The emphasis is on trying, with sensitivity, to help anyone who is having difficulty facing the need for adaptations and for the facilities which will be essential in the long term, and (for children still able to walk) to carry these out in preparation for the time when, for example, climbing the stairs becomes impossible. Because of the lengthy process involved in adaptations it will be appropriate for most families with a boy with Duchenne muscular dystrophy (DMD) to start the process when he is 6. For those children who have never been able to walk, the adaptations must be planned and completed before the child uses a wheelchair or is too heavy to be carried up and down the stairs.

The timing of adaptations for adults

The initial problem for many adults with a neuromuscular condition who are able to walk, is the increasing difficulty in getting up from a seated position; however, fortunately, there are several excellent pieces of equipment available to help (see Chapter 8b *Seat to Standing*). The correct time to start planning adaptations is when this equipment is needed, so that the work is completed before a wheelchair is essential for at least part of the day.

Should the assessment cover the short-term or the long-term needs?

In assessing the needs, there are two conflicting views as to whether the adaptations should be carried out:

- ⇒ piecemeal, to solve the problems as they occur;
- ⇒ for both the short term and long term.

Piecemeal adaptations

Adaptations should never be carried out at an earlier stage than you or your family feel is necessary, and, on a few occasions, someone disabled or their family may feel that staged adaptations are the best course of action. However, if this is because you are having difficulty looking into the future and facing the problems in advance, it will be more constructive for you to be given time and sensitive help. This will give you the opportunity to come to terms with any fears and to delay the start of the adaptations until the process has been worked through and you feel more able to plan for the future.

There are many disadvantages to piecemeal adaptations and, if possible, these should be avoided, for the following reasons:

- they involve you in intermittent upheaval;
- they accentuate any physical deterioration resulting in the need for constant psychological adjustment;
- they are likely to increase the cost in providing the necessary facilities;
- they may preclude better solutions in the future, because the initial work is not compatible structurally with the long-term plans and needs.

Adaptations for both the short term and long term

Research has shown that, for parents of a boy with DMD, the way in which the diagnosis is given and the help and support that the family receives at that time and in the subsequent months, influences their acceptance and their ability to cope.³ However, no two people are the same and reactions will vary. The core service of the Muscular Dystrophy Campaign Family Care Officers recognises the importance of giving priority to newly diagnosed families. All families need time to adjust before having to face adaptations and the need to consider the long-term solutions. This is particularly difficult when there is a delay in diagnosis, as you may then have to start adaptations before you are ready psychologically.

Catering for the difficulties in the assessment

The main emphasis is to establish the present and future housing and equipment needs, which will depend on the following:

- ⇒ understanding the condition and the progression of the disability, with reference to the medical and social model;
- ⇒ identification of the needs;
- ⇒ demonstration and trial of the most appropriate equipment;
- ⇒ suitability of the present housing;
- ⇒ availability of funding and grants.

Understanding the condition and the progression of the disability

At this stage in the discussion of the assessment of needs it is necessary to itemise the effects of neuromuscular conditions, because a knowledge and understanding of the problems experienced justifies the need, and therefore the funding, of sophisticated adaptations and equipment. The aim is not to give credence to the medical model of disability; the Muscular Dystrophy Campaign is committed to the social model of disability discussed on the next page.

The medical model of disability

It is important to establish the medical condition because the severity of the disability, the rate of progression and the possible need of a wheelchair will influence the decisions. Factsheets are available from the Muscular Dystrophy Campaign covering most types of muscular dystrophy and allied neuromuscular conditions (see Chapter 5). However, most of these conditions have several factors in common, which affect the assessment of need.

- **Most (but not all) are progressive** and the deterioration can be both physically and emotionally demanding.
- **They are selective muscle wasting conditions** (muscular dystrophies) **or conditions in which the nerve impulses fail to reach the muscles** (spinal muscular atrophy), resulting in severe muscle weakness in the legs, arms, neck and the trunk.
- **Many people either find it difficult or impossible to walk** and the wheelchair used is usually powered, because of the inability to propel a wheelchair owing to arm weakness.
- **If walking is possible, the emphasis is usually placed on the need to continue walking** for as long as possible and, when this becomes difficult, to use a standing frame daily, for as long as practical and for as many years as can be tolerated. The importance of erect posture is to delay hip and knee contractures in order to maintain the ability to lie flat and to extend the legs. Also – and even more important – this encourages a lordosis (which is a forward curvature of the spine), in order to delay a scoliosis or side curvature. This standing routine has important implications for adaptations, as it involves the need to provide work surfaces to encourage standing and the simultaneous opportunity for purposeful activities, and also the space to store a standing frame.

- **The effect of the arm weakness is particularly debilitating** and is not always fully understood. Very few people with a neuromuscular condition can raise their arms above shoulder height and, as the condition progresses, they are unable to lift their arms off the wheelchair armrests and rely on creeping with their fingers, or moving their arm by grasping clothing or a finger with teeth. This means that the height of the work surfaces needs to be very precise, so that hand function can be maximised.
- **The trunk weakness results in lack of balance** and stability making support necessary when sitting in a chair or a bath.
- **Some disabilities are stereotyped, (although the rate of deterioration is variable),** which means that adaptations can be planned for the future.
- **The muscle weakness results in sudden, extreme and abnormal tiredness,** to the extent that many adults initially use a wheelchair for part of the day only – either for specific activities or when too tired to walk. This means that the height of surfaces needs to be suitable for both standing and sitting and, because of the arm weakness, the adjustment has to be operated electrically.

The social model of disability

As long ago as 1976, disabled people themselves have been using the so-called ‘social model of disability’ to define themselves and their own experiences. The Union of the Physically Impaired Against Segregation in that year gave the following definition:

"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society".⁴

The social model today is taken to include people with all impairments – physical, intellectual and sensory – and those with mental health problems. By placing the emphasis on the barriers to disabled people’s participation in society, it provides a cure to the ‘problem’ of disability – removal of those barriers. Although it does not avoid mention of the symptoms or functional limitations linked to impairments, it does not locate disabled people’s problems entirely in their own bodies. Thus, the social model is in distinction to an individual or medical model of disability.

There is no written statement regarding agreed terminology adopted by the disability movement. However, it is generally considered that ‘disabled people’ is preferred to ‘people with a disability’ because this fits in with the social model, i.e. people are just people until they are disabled by a barrier or policy. This is supported in the writing of this manual, as the aim is to build an environment within the home that eliminates barriers and allows the maximum degree of independence in the use of the facilities.

This philosophy is shared by Selwyn Goldsmith, the architect who for many years has set the disability architectural standards. In the preface of his latest book he writes:

"The disabled' is an ambiguous term. It can mean, as it usually does, people with disabilities, those who have something wrong with them that a physician can describe. That is the medical model. Or it can mean people, whether or not they be 'medically' disabled, who are in some other way disabled – who are financially disabled, for example or socially disabled, or architecturally disabled. It is architecturally disabled people with whom this book is concerned, those who when using or attempting to use buildings can find themselves confronted by impediments which prevent them from doing so, or allow them to do so only with difficulty and inconvenience. They are disabled because the architect who designed the building did not anticipate their needs, or did not care about them".⁵

Perhaps this manual will go some way to put things right in the homes of people with neuromuscular conditions.

Identification of the needs

A *Disability Needs Assessment Form* (Chapter 10) has been compiled and piloted for several months, in preparation for the publication of this manual. The aim has been to make the assessment process as easy and thorough as possible, while at the same time identifying the choices to be made – (e.g. lift vs extension and bath vs shower), the equipment to be assessed, housing specifications to be considered – and recording the initial funding issues. In addition, these are all discussed in greater detail in this manual, as follows:

Chapter 6	<i>Lift vs Extension;</i>
Chapter 7	<i>Bath vs Shower;</i>
Chapter 8a	<i>Equipment for Adaptations;</i>
Chapter 11	<i>Justification for Funding;</i>
Chapter 12	<i>Funding of Adaptations/Understanding the Grant Systems/VAT;</i>
Chapter 15	<i>Adaptation Specifications: Access/Bathroom/Bedroom/Electrics/Heating/Storage;</i>
Chapter 16	<i>Kitchens.</i>

Demonstration and trial of the most appropriate equipment

Chapter 8a itemises the equipment that should be assessed and the order in which decisions should be made. In *every* case, it is essential that the equipment is assessed in conjunction with an OT who knows the family circumstances and whose responsibility it will be to both establish the need and justify the expense. There are three ways in which this can be carried out:

- ⇒ a visit to a Disabled Living Centre;
- ⇒ assessment in the home;
- ⇒ visiting another house where a similar adaptation has been carried out.

A visit to a Disabled Living Centre

This may be an enlightening occasion for an adult who has not received much practical help, but for parents the visit should be handled with great sensitivity and approached with a positive attitude. The aim is to counteract the disabling features of the condition and to increase the independence (and, therefore, the happiness) of the child. It should also be emphasised that the early and appropriate timing in assessing equipment will prevent delay and the subsequent frustrations in having to cope without adequate facilities. A child is likely to enjoy the visit: trying out the high-tech equipment and flying through the air in a hoist can be an interesting experience, provided that it is introduced in a positive and enjoyable way.

Assessment in the home

If an item of equipment is not held in the nearest Disabled Living Centre or if a Centre is difficult to visit, most firms will carry out a home demonstration. In addition, a specialist service has been arranged by *Daily Care* (see Chapter 18 *Addresses*) who will visit your house and bring most of the adaptations equipment on one visit. This will be much easier than having different firms demonstrating individual items. Alternatively, the firms may be able to let you know if the equipment has been installed in the area and arrangements can be made for the assessment. This may be particularly important where a realistic trial is not possible unless the equipment is plumbed into a water supply, e.g. a shower toilet.

Visiting another house where a similar adaptation has been carried out

In many cases, this is a supportive way to carry out the assessment. This may be particularly true if the adults have the same difficulties or if the children are close in age. The Muscular Dystrophy FCO or community OT may be able to make the arrangements, and this is likely to be the most satisfactory way of assessing equipment.

Suitability of the present housing

A number of factors are involved, as follows:

- ⇒ access and suitability of the garden and the area surrounding the house;
- ⇒ suitability of the existing facilities or the adaptability of the house;
- ⇒ the importance of space;
- ⇒ recommended size of rooms;
- ⇒ the use of existing rooms;
- ⇒ the need for a disabled child with a neuromuscular condition to have a separate bedroom.

Other issues will be involved if moving is considered, and these are included in the discussion on the outcome options (see page 12).

Access and suitability of the garden and the area surrounding the house

The importance of access into the garden and a suitable paved area is discussed in Chapter 15 *Adaptation Specifications*. The area surrounding the existing house is not usually of great importance, because a powered wheelchair can climb a gradient of 1 in 4 and any road is unlikely to be as steep (although this is frequently a problem with private drives). Although a sloping site should be avoided when selecting a new house, this feature in the existing house need not be the sole reason for a family move.

Suitability of the existing facilities or the adaptability of the house

- The aim is to ensure that there are en-suite facilities with a bedroom and bathroom large enough for the person (and partner) and for the essential furniture and fittings, in addition to adequate circulation space for a wheelchair. See Chapter 11 for details of the space requirements.
- Are these facilities currently available either on the ground floor or upstairs? If upstairs,
 - Can a through-floor lift be installed (i.e. is there a suitable position on the ground floor with a suitable position directly above – either on the landing or in the bedroom) or are the stairs suitable for a wheelchair-platform lift?
 - If a through-floor lift is proposed up to a bedroom, is the room large enough for both the lift and for the fittings that are needed in the room?
 - If not, is the garden suitable for a large-enough extension?

The importance of space

This should not be underestimated and frequently is the reason for adaptations needing to be reconsidered within 5 years of completion. It is important to justify the need for space to either of the following:

- a grants officer, to ensure that the proposed extension is large enough when there is concern about the cost;
- a planning officer or Planning Committee who are anxious to reduce the size of an extension.

This information has been presented in Chapter 11a *The Long-Term Housing Needs, including the Importance of Space*, and Chapter 11b *Space Requirements*, to enable them to be photocopied, and submitted with other information to justify the need for space.

Recommended size of rooms

Questions are frequently asked about the optimum size of the rooms. These are difficult to answer without details of access, the shape of the rooms, the number and size of windows and (if an extension is to be built) how this will dovetail with the existing house. It is more constructive for the architectural designer to be given an accurate brief early in the process; when the essential features and space dimensions have been considered. These will determine the size of the rooms.

The use of existing rooms

There may be several issues to be discussed on the number and use of existing rooms, which may include the need to retain the following:

- ⇒ a dining room;
- ⇒ a room for a temple or a room to be used for prayer;
- ⇒ a spare room for a carer.

The need to retain a dining room

Grants officers are responsible for seeing that the grant is spent appropriately. In this respect, they may suggest that a dining room is used to provide a ground-floor bedroom. However, this is not practical for someone with a neuromuscular condition. It is essential to have wheelchair access under a dining-room table in order to have a surface large enough to support the forearms and to provide adequate space for the dinner plate, side plate and mug; the use of a wheelchair tray is not adequate for meals.

For many families, quality family time is achieved when sharing a meal around a table and, for active families, this may be the only opportunity to talk and listen to each other. Many disabled people do not have the same opportunities as others to go out in the evenings. The ability to entertain friends at home may be an important factor to prevent isolation, and to provide a break from caring for someone who is severely disabled. Some families may need the dining room for business entertaining.

Where a dining room adjoins the sitting room, creating a throughroom may increase the wheelchair circulation space and provide a family room. In the same way, a kitchen and dining room may be opened up to create a kitchen/diner and thereby improve access, increase circulation space, or borrow natural light where a window has been lost due to the building of an extension.

The need to retain a room as a temple or a room to be used for prayer

This need is the easiest to establish as race relations and racial tolerance are recognised as important and clearly understood. It is also important to respect the Asian tradition of having separate sitting rooms for men and women.

The need to retain a spare room for a carer

One of the great distresses to anyone disabled and their partner (or parents) is that their private lives become exposed when they ask for help from a statutory service. It can be difficult to explain the need to retain a spare room. Many disabled people can be very restless at night and, for a partner who has to work the following day, it is often essential to retain a room in which they can periodically get a less disturbed night. This may be particularly important when either is ill or recovering from an operation.

It may also be necessary to accommodate a carer, on a temporary or permanent basis – or friends who stay overnight to help. To have extensive adaptations carried out that would not be adequate in the future and would involve either restarting the adaptation process or involve re-housing, is shortsighted and will prove more expensive in the long term.

A bed-sit is invaluable if a carer is needed for a teenager or young adult living at home with parents; problems can arise if the carer has to share the living area with the rest of the family, who subsequently lose their privacy, resulting in the build-up of family tensions.

The need for a disabled child with a neuromuscular condition to have a separate bedroom

Many children need attention in the night and it is unfair to constantly disturb another child sharing the room, who will then be tired at school the next day. Where a family has two affected children, if the parents get up to see one child and the other is disturbed, the parents will never get back to bed. Giving attention to both children at the same time does not always reduce the number of times it will be necessary to get up; repositioning is to increase comfort when necessary, rather than to turn the disabled child routinely to prevent pressure sores. An age gap – and therefore a difference in bedtimes – may also make it unsatisfactory for two children to share a room.

Availability of funding and grants

These are considered in Chapter 12 *Funding of Adaptations*.

The outcome options

Having assessed the needs, and considered the suitability of the present house – and depending upon the financial circumstances – a decision will need to be made between the following:

- ⇒ adapting the house;
- ⇒ moving.

Adapting the house

Before adapting a house, it is wise for the grant applicant, or their family, to give serious thought to the proposals. If there are any doubts, re-housing – or house-hunting, if you own your own house – should be considered. It is essential, where it is decided to go ahead with the adaptations, to be certain that all the alternatives were carefully examined for reassurance that the right decision was made. It is also important that, if you have any misgivings during the adaptation process, you should voice these doubts and be prepared to reconsider the alternative options. If this is difficult, it may help to enlist the support of a Muscular Dystrophy Family Care Officer.

Architectural services are grant eligible. However, a Disabled Facilities Grant (DFG) or an Improvement Grant will not be approved unless the adaptations are carried out. If the adaptations do not go ahead, it will be necessary to pay the architectural designer for the work completed without a grant to cover the cost.

Dissatisfaction with the proposed adaptation plan

In owner-occupied houses it is important to remember that the house belongs to the grant applicant or the family: you are the people who have to cope with the disability in the home and the grant is payable to you. Details of the grant are included in Chapter 12 *Understanding the Grant Systems*, but if the plans are not what you or your family feel that you need, it is important that your concerns are voiced. This is equally important in rented property. If there is disagreement on the best options and a position of stalemate is reached, discuss with the grants officer about drawing up alternative plans. Provided that the two sets of plans are equally suitable from the disability point of view, they can be priced separately, the grant paid on the cheaper scheme and you could be given the opportunity to pay the difference and build your preferred plan.

Moving

There are a number of issues to be considered:

- ⇒ social and family factors;
- ⇒ long-term housing needs;
- ⇒ housing pitfalls to avoid;
- ⇒ suitability of the proposed house, if necessary with adaptations;
- ⇒ re-housing to a rented property;
- ⇒ advice before accepting a re-housing offer;
- ⇒ mortgages for disabled people;
- ⇒ buying or renting a bungalow;
- ⇒ building a new home.

Social and family factors

The importance will vary according to the priorities of each individual family:

- Is the timing right psychologically for everyone concerned?
- Will the move involve losing the support of neighbours, friends and relations?
- Is there an appropriate school for the disabled child, within reasonable distance?
- Will the move affect the rest of the family, including the education of siblings?
- The needs of siblings are discussed in the publication *Hey, I'm Here Too*.⁶
- What are the local facilities?
- What effect, if any, will a move have on the jobs or careers of the family?

Following a move to a suitable house that needs adaptations, a grant application can be made in the normal way.

N.B. Because bungalows offer ground-floor accommodation, there may be difficulties in justifying the need for adaptations. See further advice on page 16.

Long-term housing needs

When making a re-housing application, it is important to be clear about the housing needs, as this information will be essential to send to the lettings officer of the Housing Department or to the allocation or development officer of a Housing Association.

Separate pages have been prepared on the long-term housing needs and the need for space, and are included in Chapter 11. They can be photocopied to include with applications.

Housing pitfalls to avoid

Houses built into a hillside

The expense of excavating the site and building retaining walls will reduce the amount of funding available to provide the access and facilities needed.

Houses with insufficient space for an extension at sides or rear

It would be unusual to gain planning consent for an extension other than a porch on to the front of the house, unless it is not in front of the building line.

Where an extension would be too narrow without building up to the boundary or impacting on neighbours

Look to see if a precedent has been set by extensions to other houses in the road.

Suitability of the proposed house, if necessary with adaptations

Ask for advice before making the final decision on whether to accept a lease or to buy a particular house, to ensure that, if it needs to be adapted, it is suitable. There are some houses that are either impossible to adapt or that would prove so expensive as to be impractical. Seek this advice from someone that you can trust and who will be considering your best interests – and the best person to help you will be an architect/designer with relevant experience, a Muscular Dystrophy Family Care Officer or an OT.

The dilemma for some LA personnel looking at a house before purchase, may be that their responsibility is to look for the cheapest way to adapt it. If the house is suitable for a lift, there may be the temptation, in the case of a disabled child, to dictate how the bedrooms should be allocated, suggesting that the child uses the double room intended for the parents. Where there is a dining room, it may be insisted that this is used as a bedroom, making it more difficult later to argue the case for retaining a room for meals.

Re-housing to a rented property

If you rent your home you may choose to remain in rented property or you may have no alternative. You will have to apply to be re-housed in a more suitable council house or a Housing Association or privately-owned property. However, if you are a council tenant and would consider buying a house, you should enquire if the LA operates an incentive scheme which provides capital to help families to move out of the rented sector.

Advice before accepting a re-housing offer

The following must be discussed:

- ⇒ the suitability of the house;
- ⇒ availability of grants;
- ⇒ the willingness of the Housing Department, Housing Association or private landlord to adapt the property, if necessary;
- ⇒ rent;
- ⇒ security of tenure.

The suitability of the house

See page 9.

Availability of grants

This issue is discussed in Chapter 12 *Funding*.

The willingness of the Housing Department, Housing Association or private landlord to adapt the property, if necessary

This should be discussed with the community OT and a commitment received in writing from the appropriate department, before accepting the property. If the adaptations cannot be carried out before moving into the house, the commitment should also include a time-scale for the work to begin – and the arrangements for alternative accommodation, if it proves impossible to remain in the house with builders on site.

Rent

Housing Association property can be expensive to rent and, if you are not receiving housing benefit, it may be wise to discuss the proposed rent before being re-housed or before a house is purpose built.

Security of tenure

There may be a number of issues, including security of tenure, which will be relevant to rented property irrespective of who owns the house. These should be checked out with care, with legal advice if necessary. A solicitor can be contacted at a Citizens Advice Bureau or at the nearest Disability Law Centre – both of which will be listed in the telephone directory – or by contacting the Disability Law Service (see Chapter 18 *Addresses*).

If the property has been specifically built or adapted for a disabled person, or is to be adapted for them, the partner or family should find out what the future position would be if the person dies:

- Will you be allowed to remain in the house or be asked to move?
- If you have to move, how long will you be allowed to stay after the bereavement (as it is difficult to cope with a move while the grieving is very acute)?
- If the house belongs to a Housing Association, will you be offered another of their properties or will you have to go on to the council housing waiting list?
- Will you be allowed to wait until you have been offered a house that you like – in an area in which you want to live – or will you be expected to accept the first offer?

Mortgages for disabled people

Do not assume that disability and possibly a shortened life expectancy make it impossible to get a mortgage. Seek advice from building societies or independent financial or mortgage advisors.

Buying or renting a bungalow

A bungalow can be the ultimate solution for anyone unable to climb stairs or using a wheelchair. However, before thinking of moving to a bungalow the following should be considered:

- ⇒ advantages of a bungalow;
- ⇒ disadvantages of a bungalow;
- ⇒ the need to justify adaptations;
- ⇒ advice before purchase.

Advantages of a bungalow

- ***Instant access to every room in the home***

Clearly, this is the main reason for choosing a bungalow, and is achieved with none of the disadvantages of a lift. The advantages of single-floor accommodation are:

- if a child needs attention in the night, the parents do not have to go downstairs;
- disabled parents who are unable to climb stairs, will be able to go into their children's bedrooms;
- it is feasible for anyone unable to climb stairs to assume the responsibility for supervision of the maintenance and cleaning of the house.

Disadvantages of a bungalow

These are as follows:

- ⇒ cost;
- ⇒ noise;
- ⇒ situation;
- ⇒ difficulty in justifying adaptations.

- **Cost**
The cost of a bungalow is much greater than the equivalent floor area in a house and, as a result, you may have to buy a bungalow smaller than ideal and/or increase your mortgage. The size of the mortgage is not taken into account in the ‘Test of Resources’; the means test of the Disabled Facilities Grant (DFG). These additional outgoings may make it impossible to pay your assessed contribution.
- **Noise**
There is no ceiling to deaden the sound of your children’s music!
- **Situation**
If the bungalow is sited among other bungalows, you are likely to be surrounded by older people who may be less tolerant of children and their noise.
- **Difficulty in justifying adaptations**
When considering buying or renting a bungalow you must be aware of the problems you may subsequently experience in obtaining a grant for adaptations, as the bedroom and bathroom are already on the ground floor. It is easier to justify an extension for a disabled person who has an upstairs bedroom and who cannot climb stairs or who uses a wheelchair. It may also be difficult to convince the landlord of a rented bungalow that adaptations are essential.

The DFG legislation includes a number of facilities for which grant is mandatory and in the context of this discussion the following are relevant:

“facilitating access by the disabled occupant to:

- *and from the dwelling or the building in which the dwelling or, as the case may be, flat is situated;*
- *a room used or usable as the principal family room;*
- *or providing for the disabled occupant, a room used or usable for sleeping;*
- *or providing for the disabled occupant, a room in which there is a lavatory, or facilitating the use by the disabled occupant of such a facility;*
- *or providing for the disabled occupant, a room in which there is a bath or shower (or both), or facilitating the use by the disabled occupant of such a facility;*
- *or providing for the disabled occupant, a room in which there is a wash hand basin or facilitating the use by the disabled occupant of such a facility”;*⁷...

In a bungalow the ‘disabled occupant’, will have access to *a room for sleeping and a room in which there is a lavatory, bath, shower or washhand basin* and may be denied a grant to provide a bedroom and bathroom which are both *large enough and adjacent* for provision of en-suite rooms. If you or your family try to help yourselves by moving into a more suitable home and use up your savings in the process, it is an injustice if you are then denied a grant. If necessary, this must be challenged. Had you remained in your previous house you would have been given (depending upon need and the means test) a DFG (England, Wales and Northern Ireland) or Improvement Grant (Scotland) with the possibility of a top-up grant or loan to provide an accessible and en-suite bedroom and bathroom. See Chapter 12 *Funding of Adaptations*.

The need to justify adaptations

- **The need for en-suite facilities**

It is recommended that everyone with a neuromuscular condition, who needs a wheelchair or will need one in the future, should have en-suite facilities. This enables them to be undressed on their bed and be taken to the bathroom (possibly on an extended track of the ceiling hoist) within the warmth and privacy of the two rooms.

The provision of en-suite facilities *is* a real need and, if the bathroom or bedroom is too small to allow sufficient space for the additional door, necessary equipment and the circulation space for a wheelchair, then an extension *is* needed.

Advice before purchase

When considering moving to a bungalow, it may be wise to involve the Muscular Dystrophy FCO and subsequently to check the position with the community OT, who can be contacted through the local Social Services Department. The alternative is to seek other advice – or be prepared to fight the case after purchase.

Building a new home

Replacement grants are available in Northern Ireland and these are discussed in Chapter 12 *Funding*. In the past, in the rest of the UK, although it may sound illogical, if you decided to build, there were no Housing Department Grants unless you moved in first and then asked for adaptations – and in some areas this may still be the situation. However, the Social Services Department will usually provide a ceiling hoist and may consider helping with essential fittings such as a lift, shower toilet, specialist bath and washbasin.

With the introduction of amendments to the grants system in 2003, depending upon the LA's policy, discretionary grants/loans may be available to help with the purchase of a more suitable house and this might extend to the provision of purpose-built facilities within a proposed 'new-build' house. It would be wise to approach the community OT or grants officer as early as possible, to discuss the options of both financial help and/or the provision of equipment.

References

- 1 Oldham, Christine, Beresford Bryony. *Homes unfit for children: Housing disabled children and their families*. Policy Press in conjunction with the Joseph Rowntree Foundation, 1998.
2. *Code of Ethics and Professional Conduct for Occupational Therapists*. College of Occupational Therapists, 2000, pg. 5-6.
3. Green, Josephine M, Murton, Frances B. *Duchenne muscular dystrophy: The experiences of 158 families*. Centre for Family Research, University of Cambridge, 1993.
4. Oliver, Mike. *Understanding Disability: From Theory to Practice*. Macmillan Press, 1996.
5. Goldsmith, Selwyn. *Designing for the Disabled*. Architectural Press, 1997.
- 6 Siegel, Irwin M. *Hey, I'm Here Too!* Muscular Dystrophy Campaign, 1998.
- 7 *The Housing Grants, Construction and Regeneration Act 1996, Chapter 53*. HMSO, pg. 13-14.